

# Why are we Poor Organ Donors: A Survey Focusing on Attitudes of the Lay Public From Northern India

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**Background:** Knowledge, sociocultural views, and awareness about organ donation in the general population are important for the success of deceased organ donation. There is an urgent need to gather this information in order to find out the reasons for poor organ donation rates in India. **Methods:** A 30-item questionnaire was designed in the English and Hindi language and was administered to the lay people in order to assess their knowledge, views, and attitude regarding brain death and organ donation. **Results:** Three hundred and fifty-two people (male: female = 202:150; mean age =  $30.6 \pm 13.9$  years) completed the questionnaire. Only 70% of the people were aware that the organs can be donated after brain death and only 44% thought that they understood the meaning of brain death. Media and Internet were the preferred sources for seeking information on brain death and organ donation. The majority of people (81.2%) were willing to donate organs after brain death but only 1.4% had registered for organ donation. Lack of awareness (80.1%), religious beliefs and superstitions (63.4%), and lack of faith in the healthcare system (40.3%) were believed to be the most important reasons for poor deceased organ donation rates in India. The survey also highlighted the importance of the opinion of family members and the religious leaders in making the decision for organ donation. Educational qualification above matriculation was significantly associated with the knowledge of brain death and the willingness for organ donation. **Conclusion:** Lack of awareness appears to be the most important factor for low donation rates in India. Educating people by using media and Internet and conducting awareness programs may help in improving the donation rates. (J CLIN EXP HEPATOL 2016;6:81–86)

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Organ donation is a noble act that shows our concern toward fellow human beings who are desperately in need of those organs. In an ideal situation, organ donation is an act of altruism on the part of donor and there should be no other motives attached to it. Indian culture takes pride in moral values like charity and self-sacrifice. This is depicted by a well known mythological story of the sage 'Dadhichi,' who donated his bones for making weapons in order to help the Gods to defeat the demons and reclaim the heaven.<sup>1</sup>

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**Abbreviations:** NOTTO: National Organ & Tissue Transplant Organization; OPD: outpatient department  
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In another mythological tale, King Shibi donated his own flesh to a hawk in order to save the life of a dove.<sup>1</sup> King Shibi also offered both his eyes for the restoration of a blind man's sight.<sup>1</sup> These and numerous other examples show that Indian culture and values support organ donation, and therefore, majority of people should be willing for organ donation. But the actual organ donation rates of 0.16 per million population in India are abysmally low as compared to America's 26 and Spain's 35.<sup>2</sup> Given the large number of fatalities related to road traffic accidents, there is huge potential for deceased organ donation in India and it has been estimated that organ requirement would be met even if only 5–10% of potential donors become actual donors.<sup>3</sup> The organ donors come from the society and the knowledge, sociocultural views, and awareness about organ donation among various population groups in society shape the attitudes of people toward the concepts of brain death and deceased organ donation. Thus, the information on the knowledge, attitudes, and practices of people with regard to deceased organ donation is very important; but only a few studies<sup>4–7</sup> have addressed this issue. This study aimed to assess the awareness of the brain death and the concept of deceased organ donation among lay people and to identify the potential reasons for the low rates of deceased organ donation.

## METHODS

The study was conducted from July 2012 to January 2014 in the department of Gastrointestinal Surgery and Liver Transplantation, All India Institute of Medical Sciences, New Delhi. The study was approved by the Institute's Ethics Committee. A questionnaire was designed to assess the awareness and attitude of the general population regarding brain death and organ donation. The questionnaire was designed in Hindi (Annexure I) as well as in the English (Annexure II) language. The questionnaire was initially administered to 10 lay people as a trial and suggestions were invited. Based on these suggestions, further changes were made and the questionnaire was finalized. The final questionnaire consisted of thirty questions and included yes/no based and multiple response based questions. Some multiple response questions allowed selection of a single response while others allowed selection of multiple responses. The questionnaire also required demographic details like age, gender, religion, and educational status. A single male investigator (RP) administered the questionnaire to the target population. After an initial introduction, the participants were explained about the purpose of the study and were asked to complete the questionnaire if they consented for the same. The investigator clarified the general queries of the participants and also explained the meaning of the questions if they had any problem in understanding them. However, the specific information that could have an impact on questionnaire responses was withheld and participants were told that they could clarify all their queries after completing the questionnaire. Participants who could read and write were encouraged to fill up the questionnaire themselves. The investigator read out and explained the questions to the illiterate participants and marked the responses selected by them. The inclusion criterion was the ability to understand the questionnaire in either language (Hindi and English). We did not exclude any person on the basis of religion or caste. Hence, children below the age of 12 years, those who could not understand either English or Hindi, or those who said that they did not understand the questions being asked were the only exclusions. The participants for the survey were chosen as follows:

- a) The people attending the health exhibitions and public lectures organized at All India Institute of Medical Sciences, New Delhi from time to time. These include school and college students, teachers, and local residents.
- b) The people accompanying patients visiting the outpatient department (OPD).

Statistical analysis was done using Statistical Package for the Social Sciences (version 17.0; SPSS Inc., Chicago, IL, USA). Responses for each question were expressed as percentage. A chi-square test was used for the comparison of qualitative data and a *P* value <0.05 was considered significant.

## RESULTS

The questionnaire was administered to 400 lay people, who included patients' relatives attending the OPD, people attending scientific/health exhibitions, school children, college students, and teachers. Of these, 48 incomplete questionnaires were rejected. Thus, 352 questionnaires were available for analysis. There were 202 male and 150 female respondents. The mean age of respondents was  $30.6 \pm 13.9$  years; majority of them were Hindus and around half were diploma holders/graduates/postgraduates (Table 1).

Out of all the people included in the survey, 85.5% were in the age group of 15–49 years and 98.9% were literate. However, according to the population data from 2011 census, only 58.7% of people in Delhi were in the age group of 15–49 years and the literacy rate was only 86.2%.<sup>8</sup>

Most respondents were aware that transplantation may benefit patients suffering from organ failure (93.5%) and that there is shortage of donated organs (96%), while only 69.3% were aware that the organs could be donated after brain death. More people were aware about eye (85.8%) and kidney (83.5%) donation as compared to other organs like liver (77.0%), heart (66.8%), lungs (56.0%), heart valves (55.1%), and bones (50%). Only 44% of lay people were confident about their knowledge and understanding of brain death and majority of them had received this information from media (41.2%) and Internet (24.4%). Media (31.3%) and Internet (35.5%) were also the preferred sources for seeking such information in future.

Only 56.8% of lay people had seen a poster regarding organ donation. Only around 10% of respondents had known anybody who required or had undergone a transplant. Most people (82.6%) were willing to accept an organ from a deceased donor for their relative. Only 55.1% of lay people were aware about donor cards and donor registration and only 1.4% had registered themselves as organ donors, but 71% were willing to apply for it. Majority of people (81.2%) were willing to donate organs after brain death.

Lack of faith in healthcare system (42.9%), religious beliefs (41.7%), and fear of disfigurement (35.7%) were the most common reasons for not donating organs among the people who were not willing to donate organs. Most people (88.4%) thought that views of the family are important in decisions regarding organ donation and 40.9% of people would change their decision for organ donation if it was not supported by their family. Around 37% of respondents wanted to know or were influenced by the opinion of their religious authority/spiritual guru in deciding about organ donation.

Most respondents (72.4%) believed donor willingness to be the most important factor in deciding organ donation. In case donor willingness was not known, 44.9% of people felt that the decision should be made by the next of kin and only 14.8% thought that hospital authorities should be

**Table 1 Demographic Profile of the Participants.**

Demographic parameters		Frequency (%) (N = 352)	Relevant population data (Delhi) census 2011 <sup>8</sup>
Age (years)	Less than 15	7 (2.0)	Only 58.7% in 15–49 years age group
	15–19	89 (25.3)	
	20–29	115 (32.7)	
	30–39	59 (16.8)	
	40–49	38 (10.8)	
	50–59	26 (7.4)	
	60 or above	18 (5.1)	
Gender	Male	202 (57.4)	868 females per 1000 males
	Female	150 (42.6)	
Educational qualification	Illiterate	4 (1.1)	Literacy rate: 86.2%
	Up to matriculation	61 (17.3)	
	Senior secondary	116 (33)	
	Graduation/diploma	115 (32.7)	
	Postgraduation	56 (15.9)	
Religion	Hindu	321 (91.2)	81.7%
	Sikh	8 (2.3)	3.4%
	Muslim	12 (3.4)	12.9%
	Christian	2 (0.6)	0.9%
	Others	9 (2.6)	1.1%

allowed to make such a decision. More than 60% people thought that family consent should be required even if the deceased is a registered donor and around 52% were opposed to the concept of ‘presumed consent.’ Most respondents (95.7%) believed that illegal organ trading occurs in India and around 78% thought that implementing a deceased organ donation program as a national policy would curb this illegal trade. The vast majority (88.9%) of people believed that public’s trust/faith in the healthcare system is an important prerequisite for the success of deceased donation program.

Almost half of the lay people thought that organ donation leads to disfigurement of the body. Most people (83.2%) thought that the treating physician is the most important person to counsel the family of a deceased for organ donation. The majority of people (87.8%) agreed with the concept of deceased organ donation. Lack of

awareness (80.1%), religious beliefs and superstitions (63.4%), and lack of faith in the healthcare system (40.3%) were cited as the three most probable reasons for poor deceased organ donation rates in India. Fear of disfigurement (29.5%), lack of government sponsored incentives (27.6%), fear of procedural delays (27%), and inappropriate counseling for deceased donation (26.4%) were also commonly cited reasons for poor organ donation rate.

There was no effect of age and gender on the knowledge about brain death and willingness to donate organs. Education status above matriculation was significantly associated with knowledge about deceased organ donation (72.1% vs 56.9%;  $P = 0.016$ ), understanding of brain death (48.4% vs 24.6%;  $P = 0.0001$ ), willingness to accept organ death from brain death (84.7% vs 73.8%;  $P = 0.037$ ), willingness to register for organ donation (77.4% vs 50.8%;

**Table 2 Effect of Education on Knowledge and Attitude Regarding Brain Death and Organ Donation.**

Parameters	Above matriculation N = 287 Frequency (%)	Up to matriculation N = 65 Frequency (%)	Odds ratio (95% confidence interval)	P value (chi-square)
Know that organs can be donated by brain dead	207 (72.1)	37 (56.9)	0.51 (0.29–0.89)	0.016
Understand the meaning of brain death	139 (48.4)	16 (24.6)	0.35 (0.19–0.64)	0.001
Would accept organ from brain dead if required	243 (84.7)	48 (73.8)	0.51 (0.27–0.97)	0.037
Would be interested to get registered as an organ donor	222 (77.4)	33 (50.8)	0.30 (0.17–0.53)	0.001
Would be willing to donate organs after death	245 (85.4)	41 (63.1)	0.29 (0.16–0.53)	0.001

**Table 3 Effect of Awareness that Organs can be Donated After Brain Death on Willingness to Donate Organs and Register as Organ Donor.**

Parameters	Aware N = 244 Frequency (%)	Not aware N = 108 Frequency (%)	Odds ratio (95% confidence interval)	P value (chi-square)
Would be interested to get registered as an organ donor	189 (77.5)	66 (61.1)	2.19 (1.35–3.57)	0.002
Would be willing to donate organs after death	208 (85.2)	78 (72.2)	2.22 (1.28–3.85)	0.004

$P = 0.0001$ ), and willingness to donate organs (85.4% vs 63.1%;  $P = 0.0001$ ) as compared to education up to or below matriculation (Table 2).

A significantly higher proportion of people who were aware that the organs could be donated after brain death were willing to donate organs (85.2% vs 72.2%;  $P = 0.004$ ) and register as organ donors (77.5% vs 61.1%;  $P = 0.002$ ) as compared to those who were not aware (Table 3).

## DISCUSSION

This survey suggested that the majority of people are in the favor of the concept of organ donation. This survey also suggested that majority of people are willing to get registered as an organ donor. But the actual donation rate of 0.16 per million<sup>2</sup> in India is dismal and only 1.4% of the surveyed people had actually registered for organ donation. Thus, there is huge difference between what people feel or say about organ donation and the actual behavior when such a situation arrives.

Lack of awareness may be one of the important reasons for this behavior. Brain death is a complex concept to understand for many people as the typical signs with which death is associated, such as “no pulse,” “no heart beat,” “no electrocardiogram activity,” and “a cold body,” are absent. In a study conducted in Portugal, only 19.9% of the patients understood the meaning of brain death, only 18.4% trusted the diagnosis of brain death, and 85.3% believed that physicians may be mistaken in confirming the status of brain death.<sup>9</sup> Thus, lack of awareness makes it difficult for people to accept ‘brain death’ as death. In an Indian study by Singh et al.,<sup>10</sup> nonacceptance of brain death was the principal reason for refusal of consent for organ donation in 83% of cases. Obtaining consent from family members is a major hurdle in organ donation. Donating organs is a big decision for an already grief stricken family, more so if they are hearing about this for the first time. Most potential donors are young adults with a head injury, who were completely healthy previously, and thus the family has to cope with a sudden loss of their loved one. People are more likely to give consent for organ donation if they are already aware of the concept of brain death and organ donation. In a study conducted in Missouri, USA, people who were more educated, had donor

cards, and had discussed about donation with their family more often became actual donors.<sup>11</sup> In another study conducted in Spain, the expressed wish of the deceased, a clear understanding of ‘brain death,’ the manners and approach of the doctors, the hospital facilities, concerns regarding the donation process, and educational level were factors that played a crucial role in the decision to donate organs.<sup>12</sup> Thus, the concept of brain death needs to be explained to the general population in a very simple and easily understandable manner.

Most people in our survey preferred media (television/radio/newspaper/magazines) and the Internet for getting this information. Thus, there is a need for good quality television and radio programs, newspaper and magazine articles, and Internet blogs for dissemination of information regarding brain death and organ donation. An innovative approach to introduce the concept of brain death in the high school curriculum will be of immense help. The teaching curriculum should also compulsorily include brain death, and every class or lecture focusing on death should also emphasize on the concept of brain death. The general population also needs to be primed that a request for organ donation to the relatives of a brain dead individual is a part of comprehensive healthcare of these patients so that they are not surprised or offended when such a request is made. People should be motivated for organ donation by human-interest stories related to organ donation and transplantation. Repetitive interventions using these methods may help in reducing the gap between the attitude and behavior of the people regarding organ donation.

Another important observation from the survey is the importance of the opinion of other family members in making decision regarding organ donation. Thus, for a successful donation, the consent of all the family members is required. Thus, any educational intervention has to target all the family members.

Many people cited lack of trust in the healthcare system as the reason for poor donation rates. This is a serious issue and needs to be addressed because the faith and trust of people are very important for the success of any healthcare program or initiative. The survey also revealed the fears of disfigurement and procedural delays attached to organ donation, which need to be sorted and clarified. It



would be helpful to get support of religious leaders/prominent society personalities for organ donation, as 37% of people in our survey were influenced by their opinion. Involvement of popular television and film celebrities for spreading awareness regarding organ donation and introducing storylines about organ donation into the popular television programs and films are other important strategies that may help improve the donation rates.

Based on our survey, we have devised following strategies on our part to educate the people about brain death and organ donation and to improve the donation rates.

- Teaching of patients and their relatives on a regular basis about 'deceased organ donation' and urging them to disseminate this knowledge further.
- Education of school children and general people who attend the health melas, health exhibitions, and public lectures by educational posters, leaflets, and by showing presentations and video clips on television monitors.
- Motivation of general public for organ donation by using interviews of actual organ recipients leading a normal life following transplantation and acknowledging the 'gift of life' from an unknown donor. This may also be helpful for a donor family to cope with the grief.

We also urge other healthcare institutions and Zonal Organ Donation banks in our country to use these methods to spread awareness regarding organ donation.

Lack of infrastructure is also considered as one of the reasons behind low rates of organ donation in India. At present, 16 centers in Delhi have been authorized by the National Organ & Tissue Transplant Organization (NOTTO) for organ retrieval and transplantation ([www.notto.nic.in](http://www.notto.nic.in)). All these centers have facilities for intensive care and also have dedicated transplant coordinators. Even if these centers facilitate at least 1 cadaveric donation in a month, there will be 192 donations in 1 year, which is 8–9 times more than the existing number. There are many other hospitals with intensive care facilities where brain dead individuals can be maintained on a ventilator and can be shifted to any of the authorized centers for confirmation of brain death and organ retrieval if the family consents. Thus, with the existing infrastructure, the donation rates can be increased substantially by increasing awareness and by motivating healthcare personnel involved in the care of brain dead patients.

Our population sample included a very high proportion of young adults (15–49 years) and very small numbers of non-Hindu communities. The educational qualification of participants was also much higher as compared to the general population. The difference in age and educational status may be because the younger and more educated people were more likely to attend the exhibitions. As per the 2011 census, Hindus comprise 82% of the total population of Delhi and 88% of the total population of New Delhi. The proportion of Hindus in our sample is slightly more than these values. This is probably due to a sampling error. Thus, our sample may not be the representative of general population; however, it has still revealed some very

important information regarding knowledge and views of people about brain death and organ donation that can be used to plan further population-based surveys.

## CONCLUSION

Despite a lay people survey in a population sample that was significantly young and had higher education levels than the urban population in general, this survey found that a majority of lay people did not understand the concept of 'brain death.' This survey also suggested that a majority of people are willing to donate organs if this decision is supported by their family, and higher education was significantly associated with the knowledge of brain death and willingness to donate organs. Good quality television and radio programs, newspaper and magazine articles, and Internet blogs are needed for educating people about brain death and organ donation. There are misconceptions related to disfigurement and religious beliefs that need to be addressed and educational/awareness programs need to target the whole families. Healthcare institutions can also play a significant role in educating people about brain death and organ donation. A larger population-based survey may be conducted to further confirm the findings of this survey.

## CONFLICTS OF INTEREST

The authors have none to declare.

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## APPENDIX A SUPPLEMENTARY DATA

Supplementary data associated with this article can be found, in the online version, at [doi:10.1016/j.jceh.2016.04.001](https://doi.org/10.1016/j.jceh.2016.04.001).

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